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Surveillance of Sight Loss due to delay in ophthalmic treatment or review: Frequency, cause and outcome

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Purpose

To determine the frequency of patients suffering harm due to delay in ophthalmic care in the UK over a 12-month period.

Methods

Patients with deterioration in vision in at least one eye of 3 lines of Snellen acuity or 15 letters on ETDRS chart or deterioration in visual field deviation of 3 decibels due to health service initiated delay in review or care were ascertained through the BOSU using prospective active surveillance involving all UK consultant ophthalmologists. Demographic details, diagnosis, cause and length of delay, and vision loss were then sought by questionnaire.

Results

238 cases reported between March 2015 and February 2016. 197/238 questionnaires were returned (83%). 28 reports were out of the study period or did not meet the case definition. Median age was 76 years (range: 1 to 98 years). Median delay was 22 weeks (range: 2 days to 5 ½ years). 72% experienced permanent reduction in visual acuity, 23% permanent deterioration in visual field. Main diagnoses were Glaucoma 42%, Age-related Macular Degeneration (AMD) 23% and Diabetic Retinopathy (DR) 16%. 18 patients were eligible for Severely Sight Impaired (SSI) or Sight Impaired (SI)

registration. Main causes were delayed follow-up (76%), lost referral (7%) and delayed treatment (8%).

Conclusion

Patients are suffering preventable harm due to health service initiated delay leading to permanently reduced vision. This is occurring in patients of all ages, but most consistently in those with chronic conditions. Delayed follow up or review is the cause in the majority of cases indicating a lack of capacity within the hospital eye service.

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Introduction

The NHS aspires to provide high-quality care that is safe, effective and focused on patient experience in pursuit of timely and compassionate care for every person who uses and relies on its services. This is, and always has been, determined by clinical need and free at the point of care (1). As part of this there are published guidelines detailing expected timescales for ophthalmic care and review which cover many common ophthalmic conditions. This includes a patient's legal right to treatment within 18 weeks of referral (1). The NHS is committed through its constitution to providing a comprehensive service available to all that aspires to the highest standards of excellence and professionalism whilst putting the patient at the heart of every decision (1), however this does not include published NHS standards or commitment on the length of time for follow-up appointments.

In 2009 the National Patient Safety Agency (NPSA) reported 44 glaucoma patients who experienced deterioration of vision, including 13 reports of total loss of vision, attributed to delayed follow up appointments over a 12-month

period (2). They reported a further 91 incidents related to delayed, postponed or cancelled appointments for patients with glaucoma where the level of harm was not known. A more recent review by the National Reporting and Learning System (NRLS) of harm/ loss of vision, using the returns of the adverse event reporting system, identified nearly 500 incidences of harm – loss or deterioration of vision (27% severe harm and 73% moderate harm) in the 2 year period between 2011 and 2013 (personal communication).

These data were sourced through a generic cross specialty system and due to their free text nature, the reports contained no specified definition of severe or moderate and were unable to accurately determine the degree of sight loss, the associated eye conditions or the demographic characteristics of the affected patient population. However, they clearly describe the occurance of potentially unnecessary sight loss. This is a situation backed up by a growing number of reported concerns from ophthalmologists based upon clinical experience and news reports in the media (3). This study was undertaken to provide a robust estimate of the number of patients suffering serious harm due to delay in review or treatment, along with levels of recorded visual acuity or field loss, patient demographics, diagnosis, as well as the cause and length of the delay.

Materials and methods

Patients were identified prospectively using a system of nationwide active surveillance through the British Ophthalmological Surveillance Unit (BOSU) monthly reporting card system (4). All consultant or associate specialist ophthalmologists with clinical autonomy in the United Kingdom form the reporting base for the BOSU surveillance scheme. Each month they are sent a reporting card by BOSU requesting them to report if they have seen in the preceding month any patient with the conditions currently under surveillance. The BOSU then informs the respective study investigators which ophthalmologists have reported a case and the study investigators then contact the reporting ophthalmologist.

For the 12-month study period between March 2015 and February 2016 inclusive, ophthalmologists were asked to notify the study investigators, through the BOSU, of any of newly presenting patients who had sight loss due to delay in review or treatment. The definition of harm due to delay was defined as a deterioration of vision in at least one eye of 3 lines of Snellen acuity (or 15 letters on the ETDRS chart) or deterioration in the visual field of 3 decibels or patients whose vision has deteriorated to below that measured on the Snellen Chart to Counting Fingers or worse due to a health service initiated

delay in ophthalmic review or care. Delays caused by the patient's failure to attend (DNA) were not included.

Reporting ophthalmologists who notified the BOSU of a case were sent a questionnaire that sought information on the patients age, gender, ethnicity, diagnosis, cause and length of delay and deterioration in vision. Ophthalmologists who did not return the questionnaire were sent a reminder letter to increase the response rate.

To improve the accuracy of the estimate of frequency, duplicate reports in the absence of any patient identifiers were recognised using probability matching of age, hospital, and date of appointment after delay.

This study was given approval by the NHS Fife R&D department in January 2015.

Data were recorded in a Microsoft Access database. VA data were collected as recorded in the hospital notes, loss of vision was calculated using the raw data before being converted into lines on a Snellen chart equivalent.

Results

238 cases were reported to the BOSU during the 12 month study period and 197/238 questionnaires were returned (response rate 83%). In total 28 case reports were subsequently excluded from the study (4 duplicate reports, 11

did not meet the threshold for sight loss detailed in the case definition and 13 referred to patients presenting before the study period). 169 confirmed cases meeting the case definition during the study period were identified.

Patient demographics

The median patient age was 76 years with a range of 1 year to 98 years. The distribution by life stage is shown in table 1.

54% of the patients were male and 93.4% recorded their ethnicity as White, 1.8% as Asian an 4.8% as Black.

Diagnosis and visual loss

The most frequent diagnoses were chronic conditions that required regular follow up (figure 1)

There were incomplete visual data for 26 patients. For the 106 patients with a reported loss of acuity there was a median loss of the equivalent of 4 Snellen lines of acuity (range 1 to 9 lines) (table 2). Patients reported to have a loss of less than 3 lines either had an acuity of CF or worse or had associated field loss.

Comparative visual field data were available for 46 patients. The median loss was 7 decibels with a range of 2 to 20, and 23 patients with a loss of greater than 8 decibels.

132 patients experienced a permanent deterioration in vision. 98 had permanent loss of acuity, 28 had permanent deterioration in visual field, and 6 had permanent deterioration in both acuity and visual fields. 13 patients were reported to have suffered a temporary loss of vision due to their delay in treatment or review but, of these, 9 required an unplanned surgical procedure. In addition, 6 patients with permanent deterioration in vision required an unplanned surgical intervention and 6 patients required to be admitted to hospital as an emergency. Twenty patients were reported to be eligible to be registered as severely sight impaired (blind) and 22 as sight impaired (partially sighted).

Cause and length of delay

The main cause of delay (80% of cases) was a follow-up appointment that occurred beyond the clinically recommended time. (figure 2).

The median delay beyond the intended follow-up period was 22 weeks with a range of 2 days to 5 ½ years, with 26 patients experiencing a delay of over 12 months. The proportionate delay as a multiple of planned follow-up (actual follow-up time/ planned follow-up time) is shown in figure 3. The median was 2.8 times the planned follow-up time, with a range of 1.07 to 71 times.

Discussion

This study demonstrates, through nationwide prospective data collection, that patients who are within the hospital eye service are losing vision because of delays in their intended care. The main cause was a delayed follow-up appointment beyond the clinically recommended interval, which occurred in 80% of affected patients. The majority of patients had chronic conditions requiring continuous long term follow-up, similar to that reported at Moorfields Eye Hospital (5) and this is likely to indicate an association between patient need and lack of health service capacity. The commonest reported diagnosis was glaucoma, a condition for which delayed follow up has previously been reported as a preventable cause of loss of vision (6,7). Within the context of an aging population, in which the estimated prevalence of glaucoma increases from 0.3% in the 40 – 50 year olds to 3.3% in those over 70 (8), demand upon the health service to provide care continues to increase.

At present, in contrast to appointments and treatment following initial (or new) referrals there are no targets or penalties imposed for hospitals that delay or re-book follow-up appointments to beyond the time interval recommended by the clinician. It is probable, and recognised by clinicians, that due to the requirements to meet the 18 week referral to treatment targets (RTT), hospitals are prioritising new referrals over reviews (7). This is despite

review patients being significantly more likely to have confirmed pathology that may lead to vision loss and as demonstrated, delays for follow-up patients are resulting in this form of harm.

The number of cases reported in this study represents the minimum frequency during the defined study period. Cases for this study were ascertained through a well-established surveillance methodology shown to be effective (9, 10) and to work in the UK healthcare context (4). However, it is probable that there is a degree of underascertainment. Previous reports for studies identifying cases through the BOSU have indicated that ascertainment rates usually lie between 65% and 95%.(4,11).

Although not directly linked to ascertainment, response rates are the most common method for assessing underascertainment (9). Higher response rates do correlate with better overall ascertainment (12), which means that the BOSU card return rate of 76% and the questionnaire return rate of 83% during the study period indicate high levels of compliance. This suggests that this study's ascertainment was in line with other previous BOSU studies. Adjusting for underascertainment would provide a potential likely frequency of between 178 and 260 cases per year (between 15 and 22 cases per month in the UK).

The BOSU reporting scheme is dependent on voluntary reporting and there is evidence of good compliance from reporting ophthalmologists. However, the effects of systematic under-reporting should be considered, for example where reporting cases may have been perceived to affect the reputation and future care provision within an organisation, despite the investigators clearly stating that all data would be amalgamated before being published.

The NRLS estimated approximately 250 cases of harm due to delay per year (personal communication). This is a similar figure to one we report; however, it should be noted that their estimates were based upon adverse event reporting and there were no predetermined definitions of harm beyond the reporters' own perception of the terms moderate and severe. We have ensured that those patients reported had suffered significant deterioration of vision beyond any level that might be an artefact of measurement or that which would be expected were standard care provided. We have therefore identified a genuine source of otherwise preventable iatrogenic sight loss. This study did not attempt to measure the less explicit levels of harm. However, Davies identified 16 cases of harm occurring in 12 316 lost to follow-up clinical reviews (8). This further suggests that those identified in this study are drawn from a much larger population of patients being placed at risk of significant harm or unfavourable prognosis due to health service initiated delays.

In this study 42 patients were reported to have become eligible for sight impairment (partial sight) or severe sight impairment (blind) registration following a delay in review or treatment. Previous models of costs and outcomes have illustrated the financial benefit of preventing vision loss and blindness which is estimated to amount to £28 billion per year in the UK (13). However, patients are suffering preventable harm due to health service initiated delays and this is leading to permanently reduced vision – a problem that has been recognised for nearly 15 years. Whilst this is occurring in patients of all ages, it is most consistent in those with chronic conditions associated with aging. In common with previous reports, we have been able to identify that delayed follow up appointments are the cause in the vast majority of cases indicating a lack of capacity. The data from this study are limited to a cross-sectional description but reaffirms the need for consistent robust surveillance systems to monitor patients and the subsequent potential health benefits to provide information on trends. (5,6)

It is recognised that loss of vision impacts negatively on both physical and mental health – those with sight loss are more likely to suffer falls (14), depression(15) and to become dependent on social services at an earlier stage. For children poor vision may lead to a lifetime of difficulty in reaching full potential as well as educational and developmental challenges. For those in

the working age group, poor vision commonly precludes meaningful employment (16). It is extremely concerning that patients who are within the hospital system are losing vision because they are not receiving the care they need in a timely fashion.

The solutions lie in making collection and reporting of the intended follow up date of outpatient appointments compulsory, optimising capacity in ophthalmic out-patient departments and empowering patients to challenge delays (17).

The collection of data on the difference between the actual and intended appointment date will highlight individual patient delays and measure the shortfall in overall capacity across, not just ophthalmology, but all specialties to identify capacity deficits and where resources, systems and patient care could be improved. This would also improve individual patient safety as alerts to unsafe delays would be evident.

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